Blogging for Prostate Cancer

Ben Nathanson, a retired engineer, found his voice and a softer side of himself when metastatic prostate cancer entered his life.

December 9, 2024 By Jennifer Cook

It all started with a misunderstanding. More than a decade ago, Ben Nathanson, now 69, an electrical engineer with a wife, son and daughter, was working at IBM in Westchester County, New York. A urologist would visit annually to do digital rectal exams and PSA tests for the male staff. (See the PSA sidebar below.) One year, Nathanson's PSA was a little elevated, so he had a biopsy, which was negative.

Because his PSA tended to run a bit high, the urologist said, "Don't be alarmed if it's a little high in future tests. You can safely ignore it." However, "a little high" meant one thing to the urologist and something else to Nathanson, who had a series of PSA test results over 4.0. "I should have taken action," Nathanson says. "I realized this horrible mistake I'd made. He did not mean numbers this high should be ignored," especially given that Nathanson's father had prostate cancer.

Meanwhile, Nathanson was having increasing trouble urinating. "I figured, Well, I'm an old man, that happens," he says. When it became intolerable, in 2018, he saw another urologist, who told him his prostate was nodular. "I'd heard 'Your prostate is small,' 'Your prostate is big,' but 'nodular' I had not heard—and he did not look happy about it," he says. The doctor scheduled an MRI-guided biopsy that revealed prostate cancer.

Do-Si-Do With Cancer

Surgery to remove Nathanson's prostate was scheduled for February 2019. "The prostate was a monster," he says, and the urologist "struggled to get it out." His cancer was categorized as Stage pT2, meaning there was no evidence that the cancer had spread. "In this sort of pseudo-equilibrium of good news and bad news, the bad news was that it was ductal type, which is aggressive but so rare that they can't really generalize about it and they don't really have a targeted treatment for it," he says. "The good news was that it had not escaped the capsule, so things looked good."

In a revealing Substack blog titled “The patient is responding,” which Nathanson started in 2022, he wrote that one of prostate cancer’s “rites of passage is post-prostatectomy exultation over an undetectably low PSA,” adding, “I frolicked with this for nearly two years.” When his PSA rose to 0.22 in December 2020, he had a specialized and, at the time, unapproved PSMA PET scan to look for metastases, or mets, that could be targeted with salvage radiation.

Ben NathansonMegan Senior

The PET scan showed nothing, but the CT part of the scan revealed nodules in Nathanson’s lungs—a not uncommon finding—but they were too small to biopsy. He and the radiation

oncologist agreed to do an experiment: He would go on hormone therapy, or androgen deprivation therapy (ADT)—which aims to starve prostate cancer cells of hormones that help them grow—for three months. Afterward, the nodules would be rechecked. If they shrank, it would be evidence of prostate cancer and there would be no point in doing salvage radiation to eliminate any errant cancer cells remaining in the prostate bed.

But the nodules did not shrink, and Nathanson had 40 rounds of radiation between March and May, along with hormone therapy, which he continued until the end of 2021 "because there was some equivocal indication that maybe more is better in these cases," he says. Just as the last ADT shot wore off in March 2022, his PSA started rising, and in May, the lung nodules were biopsied and found to be prostate cancer. That July, a second PSMA scan showed that the mets were confined to his lungs.

Blogging as Therapy

A paper about the hallmarks of cancer that Nathanson read in Scientific American proved to be a revelation. "It made me realize that cancer is not just some back-alley tough; it's an extremely sophisticated disease, extremely wily. It is, in some sense, a criminal mastermind. That really changed my outlook toward cancer—that it is something worthy of my respect," he says.

"I was awed by how much the body does to prevent this kind of maloccurrence," he continues. "I had not cared about biology throughout my engineering career. This really turned me around. I had to learn more."

Nathanson launched "Progressions: a deep look at prostate cancer" on Substack on April 12, 2022, with a post titled "Meet your body's worst tenant." Subsequent posts have explained the role of the prostate ("The gland you left behind") and provided a deep dive on prostate cancer ("Your tumor's mug shot"), among other topics.

He aims to translate medical terms into ordinary English for readers. "I thought I could tell people just the stuff that's pertinent, give them enough background to absorb it."

There have been benefits for Nathanson too. He finds gratification in crafting the blogs—which involves rewriting to discover just the right turns of phrase—"coming up with the sentences that sound the way I want, the act of expressing myself in writing." Another perk is that "it's a kind of distraction…and kind of therapeutic," he says. "In a sense, I am dealing with my illness but in a way that doesn't cause me needless worry. Instead of worrying what it's like to have lung mets, I can relish the sophistication of cancer and the ingenuity of researchers and the interesting stories

that are hidden behind the jargon of journals."

Nathanson launched his second blog, "The patient is responding," in order to share news about his health. "For someone who spends so much time thinking about cancer, I actually don't like to think about my situation, and I don't like to talk about it," he says. Blog posts such as "Let's put the ease in disease," "Real men don't need testosterone" and "Party like it's 1880" reveal his sense of humor and joie de vivre.

"Cancer people can go through terrible things, but when you share them, it's hard not to think, I feel terrible for you, but why are you sharing this—because I can't help you," he says. "So that has been the goal—to share the news in a non-whiny way. When people talk to me about the blog, in some weird way, they find it uplifting. And it's intended to be."

Community Comforts

Nathanson is active with AnCan, the peer-to-peer support organization formerly known as Answer Cancer that provides virtual online support groups. Among the participants, there's a diversity of cancer subtypes, so you can learn about symptoms and treatments for rarer ones, and there's geographical diversity, which means if you live in Tulsa, for example, you can find the best oncologists there.

"As a practical matter, it's good to tell people what to expect," he says. "The illness is very isolating, and it's vital to know that other people are experiencing the same horrible symptoms—it's not just you. That's salutary in its own right." Thanks to AnCan, he has formed deep and consequential friendships with people who are also sick—as well as with those who are not.

Once a month, Nathanson moderates his AnCan group's weekly video calls, and he has served as a patient advocate on a guidelines panel for the American Urological Association, which published new guidelines for prostate cancer salvage therapy this year. He also has been a reviewer for PCRP, the Prostate Cancer Research Program, which is a part of the Congressionally Directed Medical Research Program (CDMRP) within the Department of Defense. The CDMRP is a major source of research funding, second only to the National Institutes of Health, and a main source of prostate cancer research funding. "Part of what I love about the work," he says, "is that it's a chance to learn more."

Choose the Life You Are Given

Although his own mistake might have led to Nathanson's delayed prostate cancer diagnosis, he long ago forgave himself. "I actually believe mistakes are, in a way, my religion," he says. "My entire career was about mistakes. I was a copy editor. And then, at IBM, I would go over logic designs for computer chips and my only purpose was to find the mistakes. My father, personality-wise, was a fault finder, so I know where I get it from."

Nathanson has been transformed by his illness in a way he likens to annealing a metal, where you heat and disorder the molecules and then cool them so they can realign, forming a more manageable, less brittle structure in the end. With cancer, "so many things are taken away. You have to reassess. You have to reinvent," he says. "I've had a chance to regroup, to think things over and make a fresh start. So cancer has been, in that sense, a fresh start.

"If I had just retired, who knows what loose ends I'd be at. This has given me direction, focus, new friends, a new attitude. It's not hyperbole to say it's been a rebirth."

SIDEBAR

PSA Screening

According to the American Urological Association and Society of Urologic Oncology 2023 guidelines, prostate cancer screening should be based on shared decision-making with a doctor and, if done, should start with a blood test that measures prostate-specific antigen (PSA), a protein produced by the prostate gland. It is normal to have some PSA in the blood. What's considered an elevated PSA is now thought to increase with age. Most studies have found that for people in their 40s, the threshold is 2.5; for those in their 50s, it's 3.5; for those in their 60s, 4.5; and for those in their 70s, 6.5. (Levels higher than 10 are considered above normal range.) For people at average risk for the disease, testing may begin between ages 45 and 50; for those at higher risk (Black ancestry, germline mutations or a strong family history of prostate cancer), testing should begin at age 40 to 45.

SIDEBAR

What About Sex?

Men often fear the consequences of prostate cancer and its treatment, especially the loss of their sex drive and function. The prostate, about the size of a walnut and located below the bladder, produces fluids that mix with sperm to create semen; the gland also helps propel the fluid during ejaculation. What's more, hormone therapy that suppresses androgens can lead to loss of libido. Ben Nathanson offers insights on how an intimate relationship can thrive despite these changes.

- Examine what makes sex pleasurable. So much of what we experience as pleasure is unexamined, including sex. If you stop to analyze its component parts to find out what makes sex meaningful to you, you'll see that a lot of what you need is still there—"a lot of what you're trying to gratify with sex can still be gratified."
- You likely won't miss your sex drive. "It's not like your face is pressed against the shop window and you wish you could partake in this and you can't," he says. Instead, your sexual desire may become something that is less interesting, in large part. You may feel the feelings but no longer feel wildly driven to act on them.
- Look beyond the sex act. A lot of what you want may be different from the act itself—closeness with your partner, for example.
- Enjoy the feeling of freedom. "Part of what makes sex fun for people who find it fun is the freedom to set aside their rational self and be a little more animal-like. There's no reason you can't continue to do that."
